

Ross Anderson FRS FREng
Professor of Security Engineering

Rt Hon Stephen Dorrell MP
Chair, Health Committee
Houses of Parliament
London SW1A 1AA



**UNIVERSITY OF
CAMBRIDGE**

Computer Laboratory

March 2, 2014

Dear Mr Dorrell,

Testimony on care.data

You may recall that, while you were Secretary of State for Health, I was the BMA's adviser on the safety and privacy of health IT systems.

I was interested to hear claims made before you by officials that they did not intend the personal health information collected via the 'care.data' exercise to be sold to companies, or transferred abroad, and that the extract would be based entirely on coded data, without any free text comments about the patient.

On all three counts further investigation by the committee is needed.

1. Both Tim Kelsey, the Department's witness, and your successor Jeremy Hunt signed a Memorandum of Understanding with the US DHHS on Jan 21 2014, which talks about 'Liberating Data and Putting it to Work' and 'Priming the Health IT Market'. This can be found at http://medconfidential.org/wp-content/uploads/hhsnhs_mou_final_jan_21.pdf. For what they told the press, see 'US-UK sign healthcare IT MoU', EHI Jan 23rd.
2. As for what this means in practice, you might care to look at 'Feds Praise Open Data Health Cloud Launch', InformationWeek Healthcare, 12th November 2013, where it was announced that BT would be selling access to the medical records of 50 million English patients. This is linked, with related material, from my blog at <http://www.lightbluetouchpaper.org> on November 22nd: 'Your medical records - now on sale'. The US press followed up with articles on the DHHS's pleasure and its intention to contribute some US records too; see for example 'US and UK share health data via cloud', Healthcare IT News, Nov 15.
3. You've been told that data are effectively anonymised. This is not the case. This was one of the issues which the BMA argued with the Department when you led it; you handled the issue much

Computer Laboratory
JJ Thomson Avenue
Cambridge CB3 0FD
England

Tel: +44 1223 334733
Fax: +44 1223 334678
E-mail: Ross.Anderson@cl.cam.ac.uk

better by setting up the Caldicott Committee which pointed out the risks, and which the Department then acknowledged (though the protections you left behind have been eroded by subsequent legislation). Even if postcode and date of birth are removed (which is not the case in HES), a record that links all the episodes relating to an individual patient is often easy to reidentify from context. To find Tony Blair's record, for example, you'd look for all patients who underwent cardioversion and catheter ablation at Hammersmith Hospital on October 19th 2003. Even if hospital names are also removed, you won't have to work that hard. This has been confirmed by a large body of scientific work on statistical security and inference control; see for example the Royal Society's report *Science as an open enterprise*.

4. I already pointed out to the press that actuaries have been buying HES data to refine disease-related mortality statistics and observed that they used the word 'purchase' to describe this activity, contrary to current Departmental policy on euphemisms.
5. You've been told that only coded data are collected. May I point you to Anoop Shah, "Using free text in primary care research" (http://www.ucl.ac.uk/pcph/research-groups-themes/thin-pub/research_presentations/anoop_shah_fma) where a researcher from UCL reports using text-mining techniques on free text harvested from patient records through CPRD.
6. You might also care to note that CPRD refused a freedom-of-information request about the anonymisation mechanisms that they claim will protect patient privacy: my request 'Privacy mechanisms in CPRD', https://www.whatdotheyknow.com/request/privacy_mechanisms_in_cprd. The agency claimed that revealing their protection mechanisms would compromise security. It is a fundamental principle of information security that protection is only robust if the protection mechanism can be published. The refusal to disclose how the data are protected suggests that the officials who proclaim the mechanism secure actually have little confidence in it.
7. In my role as an academic at Cambridge I've been offered access to CPRD data via our central bodies – and I don't even do research on medicine, but on computer science. It seems the Department is very anxious to build up a large user base for these systems in the face of rising public concern about whether they are ethical even legal.

It does rather appear that officials are saying one thing to Parliament, and another thing to researchers, to the industry, to the trade press and to the US government.

If patient confidentiality is undermined, or patients lose confidence in doctors' ability to keep secrets, the consequences can be grave. I enclose a briefing note I wrote for the European Commission during the recent debate on the Data Protection Regulation that summarises the evidence. If confidence is lost, many thousands of people each year will seek treatment late or not at all for a wide variety of conditions.

Yours sincerely,



Ross Anderson